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ABSTRACT

The report relates existing State Title V programs based on the Social Security Act to implications of Public Law 99-457 (the Education of the Handicapped Act Amendments of 1986), especially Part H which authorizes comprehensive coordinated statewide early intervention delivery systems for infants and toddlers with handicaps. In section I, particular attention is given to the Surgeon General's National Agenda for Family-Centered, Community-Based, Coordinated Care for Children with Special Health Care Needs and to block-grant provisions promoting community-based networks and case management services. Section II presents the 14 required components of a statewide early intervention system under the Part H statute and excerpts portions of the Part H regulations, especially those in which the terms "health," "medical," or "Title V" appear. Section III examines opportunities for State Title V programs and is organized around required components of the early intervention system. Section IV, on health and medical services under Part H, stresses that Public Law 99-457 does not fully address the spectrum of health and medical needs of young children, rendering Title V programs still important. Finally, section V reviews State Title V Program roles related to Part H, especially those under Maternal and Child Health and Children with Special Health Care Needs funding. (DB)

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HHS Region III
Perinatal Information
Consortium
Technical Report Series

Public Law 99-457:

Challenges and Opportunities for State Title V Programs

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PIC-III Technical Report Series 89-04

Public Law 99-457, Part H
Challenges and Opportunities for State Title V Programs

OVERVIEW

The existence of a variety of federal and state statutes, and regulatory and policy requirements support the present categorical nature of children and family services throughout the United States. This situation results in barriers to the goal of a comprehensive, coordinated and flexible service delivery system for children with special health care and (re)habilitative needs and their families, as well as for other vulnerable children. In response to the question posed in the title of his paper, "The Integration of Public Services for Handicapped Children: Myth or Reality," Dr. John MacQueen stated:

> Because the concept of categorical programs is so much a part of the accepted organization of state government and, because fragmented services are too often accepted as the norm, a revolutionary change will be required to achieve the goal of integrating services for handicapped children. But, lest the idea of a revolutionary change be frightening or disheartening, I would remind you that the creation of the state crippled children's program in 1934 was considered revolutionary. (p.128)

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MacQueen, JC. The Integration of Public Services for Handicapped Children: Myth or Reality. In Developmental Handicaps: Prevention and Treatment II, American Association of University Affiliated Programs (AAUAP), March 1985. [AAUAP, 8605 Cameron St., Suite 406, Silver Spring, MD 20910, Phone: (301)588-8252]
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There may be another revolution on the horizon. In 1986, the United States Congress enacted Public Law 99-457, "The Education of the Handicapped Act Amendments of 1986." This legislation

reauthorized many programs under Public Law 94-142, "The Education of the Handicapped Act" (EHA), and authorized several new programs, including Part H, a discretionary program for Infants and Toddlers with Handicaps. Part H authorizes a rigorous national agenda pertaining to a statewide comprehensive coordinated service delivery system for infants and toddlers, birth through two, with disabilities and their families. At each state's discretion, at-risk infants and toddlers, as defined by the state, may also be eligible for services under this Act.

Beginning October 1, 1990, most of the required components of a statewide early intervention program under Part H must be in place. The state system must be in place in its entirety by October 1, 1991. This means that all eligible children and their families, as defined by each participating state, will have the right to early intervention services as defined under Part H. A participating state is one that chooses to continue receiving Federal Part H funds in the fiscal year beginning October 1991, and thereafter. As an entitlement program, early intervention services must be provided under public supervision and at no cost to the family, except where Federal or state law provides for payments by families.

It is generally agreed that in order to accomplish the goal of ensuring a continuum of statewide services for infants and toddlers with disabilities and their families, consistent with the essential requirements of the Federal statute and Regulations, an unprecedented degree of interagency planning and implementation

will be required by both state and local jurisdictions. Thus, P.L. 99-457, Part H, provides a "window of opportunity" for the development of more systematic state and local interagency efforts which promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services.

However, it must be understood that P.L. 99-457 does not create a new independent program entity. Rather, it provides a program framework or structure within which the essential components, as required by Federal statute and Regulations, will become operationalized through the collaborative efforts of existing program entities within each state. In a recent joint report to Congress, the Departments of Education and Health and Human Services described the Federal commitment to the goals of the Handicapped Infants and Toddlers Program and outlined an interagency agenda to provide national leadership. This commitment for leadership must be demonstrated at the state level as well.

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Meeting the Needs of Infants and Toddlers with Handicaps: Federal Resources, Services, and Coordination Efforts in the Departments of Education and Health and Human Services, A Report to Congress by the Department of Education and the Department of Health and Human Services, January, 1989.

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States are provided with a great deal of latitude in the planning and implementation of an early intervention system. The State Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) Programs must be integral components of this effort. The purpose of this Technical Report is to discuss

both the requirements and opportunities for State Title V Programs' involvement in the development of statewide early intervention systems under Part H.

Promoting access to comprehensive and coordinated services for young children, especially those with special health care needs, is not a new mandate for State Title V Programs. The purpose of the first Section of this Report, The Title V Mandate for States, attempts to put P.L. 99-457, Part H, within this perspective. Particular attention is given to the Surgeon General's National Agenda for Family-Centered, Community-Based, Coordinated Care for Children with Special Health Care Needs and to the provisions of the MCH Block Grant Amendments, as contained in the Omnibus Reconciliation Act of 1986 (P.L. 99-509), for states to promote the development of "community-based networks and case management services for children with special health care needs." Within the context of these two initiatives, the major point intended in this section is that Part H represents a paradigm for the provision of services to all vulnerable children of concern to State Title V Programs.

Section II, The Part H Regulations, presents the 14 required components of a statewide early intervention system as required by the Part H statute, and then excerpts select aspects of the Final Regulations for Part H which, in the author's view, have direct relevance for State Title V Programs. Particular attention was given to including those areas of the Final Regulations in which appear the terms "health", "medical", or "Title V". The author

acknowledges that excerpting only select aspects here was done at the risk of diverting attention away from the importance of the Final Regulations in their entirety, and of creating some confusion on the part of the reader as reference numbers/letters within this section do not follow a consistent pattern. However, given the length of the Final Regulations, some degree of abbreviation was required for the purposes of this Report.

Section III, Opportunities for State Title V Programs, is organized around select required components of the statewide early intervention system. As suggested by the Report's title of the same name, it is hoped that the reader will find this section to be the most substantive with respect to the many implications of Part H for State MCH and CSHCN Programs. This Report recognizes the similarity of necessary roles and opportunities for State Title V Programs pursuant to Part H. Although there currently exist a variety of related efforts in many states, only initiatives within Maryland are identified for illustrative purposes.

The most important point to be made in Section IV, Health and Medical Services Under Part H, is that the Act does not, nor was it intended to, fully address the spectrum of health and medical needs of young children. Although early intervention services are to be coordinated with the child's health/medical plan of care, Part H does not provide an entitlement assuring access to such services outside the limited definition of "health services" and "medical services only for evaluation and diagnostic purposes," as defined in the Regulations. The importance of State Title V

Programs related to this area are obvious. Particular attention is given to the concept of a "medical home."

Section V, Survey of State Title V Program Roles Related to Part H, is not intended to be a comprehensive review of State MCH and CSHCN activities in this area. All states in which the health agency is the lead agency under Part H are identified. More specific contact information is provided for the Region III States. The Report ends with a brief concluding Section which emphasizes the importance of the local planning and implementation process, and the major opportunity created by Part H - an opportunity to step back from our usual ways or modes, and to develop and try new schemes in our efforts to assist young children and their families in ways that are not only more efficient, but more effective as well. There are many unanswered issues related to the implementation of Part H, particularly in the funding arena. Although we will not have it all right come October, 1990, P.L. 99-457, Part H, does point us in a forward direction to meet the challenge of assuring a comprehensive and coordinated early intervention service delivery system in each state, with particular emphasis on the interagency and family-centered aspects required of such a system.

I. THE TITLE V MANDATE FOR STATES

As contained in the Omnibus Reconciliation Act of 1981, the Maternal and Child Health Services Block Grant authorizes appropriations,

Sec. 501. (a) For the purpose of enabling each State -

(1) to assure mothers and children (in particular those with low income or with limited availability of health services) access to quality maternal and child health services,

(2) to reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children, to reduce the need for inpatient and long-term care services, to increase the number of children (especially preschool children) appropriately immunized against disease and the number of low income children receiving health assessments and follow-up diagnostic and treatment services, and otherwise to promote the health of mothers and children (especially by providing preventative and primary care services for low income children, and prenatal, delivery, and postpartum care for low income mothers),

(3) provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits under Title XVI of the Act, and

(4) provide services for locating, and for medical, surgical, corrective, and other services, and care for, and facilities for diagnosis, hospitalization, and aftercare for, children who are crippled or who are suffering from conditions leading to crippling; . . .

Additionally, the proposed amendments to the MCH Block Grant Program make explicit the goal,

. . . to provide and to promote family-centered, community-based, coordinated care (including care coordination services . . . for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families . . .

This far-reaching Title V mandate is much broader in scope than Part H which relates only to young children and is limited in its inclusion of medical and health services as early intervention

services. However, notwithstanding the significance of P.L. 99-457 in assuring a comprehensive service delivery system for infants and toddlers and their families, Part H does serve as an important paradigm for implementing the Surgeon General's national agenda for a system of family-centered, community-based, coordinated care for all children with special health care needs.

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Brewer, EJ, McPherson M, Magrab PR & Hutchins VL (1989). Family-Centered, Community-Based, Coordinated Care for Children with Special Health Care Needs. Pediatrics, 83(6): 1055-1060.

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The elements of such a system as discussed in "Family-Centered Care for Children with Special Health Care Needs," a document that has become widely known as the "Red Book," are consistent with the requirements under Part H. These elements are as follows:

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.

2. Facilitation of Parent/Professional collaboration at all levels of health care.

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.

5. Recognition of family strengths and individuality and respect for different methods of coping.

6. Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care delivery systems.

7. Encouragement and facilitation of parent-to-parent support.

8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.

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Family-Centered Care For Children With Special Health Care Needs, Association for the Care of Children's Health (ACCH), 1987. [ACCH, 3615 Wisconsin Ave., N.W., Washington, D.C., 20016, phone: (202) 244-1801]

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In response to the Surgeon General's National Agenda for family-centered, community-based, coordinated care for children with special health care needs, and under the leadership and guidance of the Bureau of Maternal and Child Health and Resources Development, the Omnibus Reconciliation Act of 1986 (P.L. 99-509) authorized an increase in the Maternal and Child Health Block Grants, earmarking a portion of these funds to the states to promote the development of "community-based networks and case management services for children with special health care needs." Additionally, this Act authorized funds for the purpose of carrying out special projects of regional and national significance (SPRANS), training and research to promote access to "community-based service networks and case management for children with special health care needs."

Under P.L. 99-509, "community-based service networks" has the following meaning:

> . . . a network of coordinated, high-quality services that is located in or near the home communities of children with special health care needs in order to improve the health status, functioning, and well-being of such children . . .

Whereas, "case-management services" is defined as:

> . . . services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children and their families . . .

Within this definition, "comprehensive services" is defined to include the following:

> . . . early identification and intervention services, diagnostic and evaluation services, treatment services, rehabilitation services, family support services, and special education services.

According to guidance from the Bureau of MCH and Resources Development, the intent of the State Program for Children with Special Health Care Needs, to be described in the Report of Intended Expenditures (RIE), should include the following:

a. family-centered elements of care;

b. community-based services;

c. coordination of services at family and community levels;

d. linkages between community networks and the specialized services in the State;

e. role of the State agency program for CSHCN (under the MCH Services Block Grant Authority) in relation to the system of care;

f. cooperative relationships between and among coalitions of public, private, and voluntary agencies and child care professions;

g. options to improve public and private insurance and other methods of financing (e.g., expanding Medicaid coverage at the State level, Medicaid waivers, State risk pools, affordable long-term care in insurance, tax policy changes); and,

h. financial education, counseling and management services for families as a component of coordinated care.

Two points should appear self-evident from these components and within the meaning of the terms community-based service networks, case management and comprehensive services: (1) State Title V Programs must be integral components of the development and

implementation of each State's early intervention system under P.L. 99-457, and (2) such a system represents a paradigm for serving all vulnerable children of concern to State MCH and CSHCN Programs.

The Habilitative Services Branch of the Division of Services for Children with Special Health Needs in the Bureau of Maternal and Child Health and Resources Development (BMCHRD) has recently designated ten National MCH Centers. These Special Projects of Regional and National Significance (SPRANS) will assist states in promoting and expanding family-centered, community-based, coordinated systems of care by providing technical assistance and consultation, enhancing networking, developing and disseminating products, convening conferences, developing data bases and resource libraries. Although not the sole focus of these Centers, they are a valuable resource to State Title V Programs with respect to the planning and implementation of various components of Part H. These designated National MCH Centers include:

* National Center for Clinical Infant Programs (NCCIP), Washington, D.C.
* National MCH Center for Ensuring Adequate Preparation of Providers of Care, Louisiana
* National Center for Family-Centered Care, Washington, D.C.
* National MCH Resource Center, Iowa
* New England SERVE, Massachusetts
* National Center for Youth with Disabilities, Minnesota
* Pathfinder, Minnesota
* National Network for Children with Special Needs, Washington, D.C.

* Federation for Children with Special Health Care Needs, Massachusetts

* Handicapped Children's Institute, Ohio

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An informational matrix describing the varied technical assistance roles of these Centers, and contact information, will be disseminated to State Title V Programs and others in the near future.

For further information about these Centers contact:
Division of Services for Children with Special Health Care Needs
Bureau of MCH and Resources Development
Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
(301) 443-2350

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Several other efforts are underway to assist states in developing and implementing the components of Part H. One of the major efforts in this area is the National Early Childhood Technical Assistance System (NEC*TAS), a technical assistance contract funded by the Office of Special Education Programs (OSEP), Department of Education, in conjunction with the Bureau of Maternal and Child Health and Resources Development. This contract is for the purpose of assessing the needs of states and other jurisdictions that participate in the Handicapped Infants and Toddlers Program and delivers technical assistance in response to those needs. NEC*TAS represents a consortium of six agencies comprised of multidisciplinary professional and parental expertise. The system is administered by the Frank Porter Graham Center, University of North Carolina at Chapel Hill. The composition of the consortium includes:

* Child Development Center, Georgetown University

* Department of Special Education, University of Hawaii at Manoa

* National Association of State Directors of Special Education (NASDSE)

* National Center for Clinical Infant Programs (NCCIP)

* National Network of Parent Centers, Inc.

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For more information on services and products offered by NEC*TAS, contact the coordinating office:

NEC*TAS
CB# 8040, 500 NCNB Plaza
The University of North Carolina at Chapel Hill
Chapel Hill, NC 27599
(919) 962-2001

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II. THE PART H FINAL REGULATIONS

The Intent and Spirit of P.L. 99-457: A Sourcebook, provides a valuable background perspective with respect to this Act. For the purposes of this Technical Report, the introductory statement to this resource document is well worth reproducing here. It reads as follows:

Dear Colleague:

The Campaign to bring family-centered, community-based, coordinated health, developmental, educational and social services to this country's young children and their families is being fought on many fronts. New ideas - generated by families, by professionals, and by the Surgeon General of the United States, among others - must be translated into legislation and administrative regulations. Effective service models must get beyond the "demonstration" or even the "replication" stage and become standard practice in every community. The Education for the Handicapped Act Amendments of 1986 (P.L. 99-457) mark an extremely important point in the revolution now underway. Drawing on the best thinking and the most promising service models offered by families, practitioners, researchers and State agency administrators, the law provides opportunities and incentives to make significant positive changes in virtually every aspect of our societal relationships with young children with disabilities and their families.

As with any piece of legislation, the full impact of P.L. 99-457 will only be seen as it is implemented. And the process of implementation includes not only much discussion at the Federal, State and community levels of the best ways to carry out the intent of the Law but also, inevitably, a great deal of discussion about what the intent of the Law really involves. The materials included in this document articulate the intent of the framers of P.L. 99-457:

* "P.L. 99-457: A Window of Opportunity" is the text of speech by Robert Silverstein, Staff Director and Chief Counsel of the Subcommittee on the Handicapped of the Senate Committee on Labor and Human Resources to the national meeting of Project Zero to Three, November 3, 1988. Mr. Silverstein discusses nine major themes that are elaborated in the provisions of P.L. 99-457 and describes their implications for States and local policy-making.

* "Report #99-860", from the Committee of Education and Labor of The House of Representatives describes the background and need for P.L. 99-457 and the rationale behind each provision of the

legislation.

* "Community-Based Service System for Children with Special Health Care Needs and Their Families", a publication prepared by the National Maternal and Child Health Resources Center for the U.S. Surgeon General's Conference in September 1988, describes a vision of family-centered, coordinated care that helped to form the conceptual foundation of P.L. 99-457.

As a charter member of the Federal Interagency Coordinating Council for P.L. 99-457, the Office of Maternal and Child Health is pleased to make these three rich and thoughtful documents available to the families, practitioners, administrators and legislators who are working so hard to make the vision of the framers of P.L. 99-457 a reality for children and families.

Sincerely yours,

Merle McPherson, M.D.
Director
Division of Services for Children with Special Health Needs

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For further information about this publication, contact:
National Center for Clinical Infant Programs
733 Fifteenth Street, N.W., Suite 912
Washington, D.C. 20005
(202) 347-0308

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On June 22, 1989, the Final Regulations for Part H of the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457), entitled "Early Intervention Program for Infants and Toddlers with Handicaps," were issued (34 CFR Part 303). These regulations were published in the Federal Register 54(119), pages 26306-26348, and have been widely disseminated. Consistent with the Federal statute, they are intended to ensure that a "statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services" is established in each participating State. Although these Regulations were issued by the Department of Education, Congress made clear that the success of

the program is dependent upon an unprecedented degree of interagency collaboration - both in the provision and financing of early intervention services.

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For a copy of or further information about the regulations contact:

The Office of Special Education Programs
Department of Education, 400 Maryland Avenue S.W.
(Switzer Building, Room 4618 M/S 2313-4600)
Washington, D.C. 20202, Phone: (202)732-1114

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The following is a list of the required essential components of a statewide system which are addressed in the Regulations:

(1) State definition of the term "developmental delay" to be used for determining eligibility under this Act;

(2) Timelines for ensuring that appropriate early intervention services will be available to all eligible infants and toddlers, and their families, prior to the fifth year of a state's participation under Part H;

(3) Comprehensive, multidisciplinary evaluation and assessment of child and family needs and strengths;

(4) Individualized family service plans (IFSP), including case management services in accordance with such service plans;

(5) Comprehensive child find system to include a means for making referrals into the statewide program by primary referral sources;

(6) Public awareness program with emphasis on the early identification of eligible infants and toddlers;

(7) Central directory of services which includes early intervention services available in the state and related resources, expert personnel and research and demonstration projects in the state;

(8) Comprehensive system of personnel development (CSPD);

(9) A single line of responsibility in a lead agency designated or established by the Governor for carrying out:

(a) the general administration, supervision and monitoring of programs and activities;

(b) the identification and coordination of all available related resources with the state from Federal, state, local

and private sources;

(c) the assignment of financial responsibility;

(d) the development of procedures to ensure that services are provided in a timely manner pending the resolution of any disputes among public agencies or other service providers;

(e) the resolution of intra- and interagency disputes; and,

(f) the entry into formal interagency agreements that define the financial responsibility of each agency for paying for early intervention services (consistent with state law) and procedures for resolving disputes, including all components necessary to ensure meaningful cooperation and coordination.

(10) Policy for contracting or otherwise arranging for services;

(11) Procedure for securing timely reimbursement of funds used under Part H;

(12) Procedural safeguards with respect to services and programs under Part H;

(13) Policies and procedures relating to the establishment and maintenance of personnel standards; and,

(14) System for compiling data related to intervention services and service populations in the state.

The major components of the statewide system are to be in place no later than the beginning of the fourth year of a state's participation (i.e., on or about October, 1990). Actual provision of all appropriate early intervention services to all eligible children and their families will occur no later than the beginning of the fifth year (i.e., on or about October, 1991).

As defined in the Regulations, "early intervention services" include (but are not limited to): audiology; case management services; family training, counseling, and home visits; health services; medical services only for diagnostic and evaluation purposes; nursing services; nutrition services; occupational

therapy; physical therapy; psychological services; social work services; special instruction; speech-language pathology; and transportation. Given the diversity of services to be made available as "early intervention services," implementation of the Regulations at the state and local levels will provide new opportunities for closer collaboration among Programs for Children with Special Health Care Needs, Maternal and Child Health Programs and other programs/agencies concerned with infants, toddlers and their families.

The requirements pertaining to the 14 essential components include many areas which have direct implications for State Title V Programs, as well as for other members of the health care community who provide early intervention and family services. Although the Final Regulations document pertaining to P.L. 99-457, Part H, should be reviewed in its entirety as it contains some substantive changes, additional guidance and clarification, and a refined structure from the Proposed Regulations, published for public comment in November 1987, only select aspects of the Final Regulations which appear to have particular relevance for State Title V Programs are noted in this Technical Report. Comment, Discussion and Change sections that accompanied select regulations are also included as they provide some perspective on the nature of the feedback received from the field in response to the regulations initially proposed.

Excerpting this material here is done at the risk of diverting attention away from the importance of the Regulations in their

entirety, and of lost intent or meaning in taking select parts of the Regulations out of their full program context. However, given the length of the Final Regulations document - approximately four times that of the document appearing in the Notice of Proposed Rulemaking, it may be of some utility, for the purposes of this Technical Report, to highlight only those which are likely to have the most direct relevance for all State Title V Programs. Of course, in those states where the Title V Program is the lead agency, all of the Regulations have direct relevance. Particular attention was given to reproducing here those areas in which appeared the terms "health," "medical" or "Title V."

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SOURCE: Federal Register, Vol. 54, No. 119, June 22, 1989. 34 CFR Part 303, Early Intervention Program for Infants and Toddlers with Handicaps; Final Regulations.

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Sections 303.5-303.23 of the Final Regulations document include definitions (in alphabetical order) that are used throughout. Only certain definitions, and select parts of the definitions chosen at that, are noted here as it is felt that such have a more direct relevance to State Title V programs.

303.6 Case management.

. . . Specific case management activities. Case management activities include -

(1) Coordinating the performance of evaluations and assessments;

(2) Facilitating and participating in the development, review, and evaluation of individualized family service plans;

(3) Assisting families in identifying available service providers;

(4) Coordinating and monitoring the delivery of available services;

(5) Informing families of the availability of advocacy services;

(6) Coordinating with medical and health providers; and

(7) Facilitating the development of a transition plan to pre-school services, if appropriate.

. . . Qualifications of case managers.

Case Managers must be persons who . . . have demonstrated knowledge and understanding about -

(1) Infants and toddlers who are eligible under this part;

(2) Part H of the Act and the regulations in this part; and,

(3) The nature and scope of services available under the State's early intervention program, the system of payments for services in the State, and other pertinent information.

Note: If States have existing case management systems, the State may use or adapt those systems, so long as they are consistent with the requirements of this part.

Comment: Some commenters requested that the regulations provide that parents be appointed as case managers for their children.

Discussion: The Secretary believes that Congress included the requirements for case managers and case management in order to ensure that, because of the interagency, multidisciplinary nature of Part H, the burden of seeking out and obtaining services guaranteed under this program would be placed upon appropriate public agencies in the State and not on the parents of eligible infants and toddlers. Thus, the statute requires that each IFSP must include "the name of the case manager from the profession most immediately relevant to the infants and toddlers or family's needs who will be responsible for the implementation of the plan and coordination with other agencies and persons."

The Secretary believes that the statutory requirements evidence a clear congressional intent that the responsibility for "case management," as that term is defined in sec. 303.6 be assigned to an appropriate, qualified public agency employee. It is also clear that the Congress did not intend for parents to have to assume this responsibility.

Although parents may not be named as case managers, the

Secretary recognizes that parents (1) must be actively involved in making sure that their eligible children and other family members receive all of the services and protections that they are entitled to under this part, and (2) are major decision-makers in deciding the extent to which they will participate in, and receive services under, this program.

Change: None

303.11 Early Intervention program.

As used in this part, "early intervention program" means the total effort in a State that is directed at meeting the needs of children eligible under this part and their families.

Comment: A number of commenters recommended that the regulations acknowledge that a comprehensive system of early intervention services should encompass all appropriate services needed by an eligible child and the child's family, not just those under Part H of the Act.

Discussion: The Secretary believes that the Congress intended that the early intervention program established under this part should encompass activities that extend beyond the provision of discrete early intervention services. He believes that the program should include the total effort in a State that is directed toward meeting the needs of children eligible under this part and their families, including (1) those functions that must be carried out as part of a State's responsibilities under this part (e.g., evaluation and assessment activities, case management, and administrative-coordinative activities related to the development, review, and evaluation of IFSPs, and implementation of the procedural safeguards); (2) specific early intervention services, as defined in sec. 303.12; and (3) medical and other services that an eligible child and the child's family may need, but which are not required under this part.

Change: A definition of "early intervention program" has been added at sec. 303.11.

303.12 Early intervention services.

. . . Are provided -

(i) Under public supervision;

(ii) By "qualified" personnel . . .
(iii) In conformity with an individualized family service plan; and,

(iv) At no cost, unless . . . Federal or State law provides a system of payments by families, including a schedule of

sliding fees;

. . . Types of services; definitions.

Following are types of services included under "early intervention services . . .

. . .(2) "Case management services" means assistance and services provided by a case manager to a child eligible under this part and the child's family that are in addition to the functions and activities included under sec. 303.6.

(3) "Family training, counseling, and home visits" means services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the family of a child eligible under this part in understanding the special needs of the child and enhancing the child's development.

(4) "Health services" (See sec. 303.13).

(5) "Medical services only for diagnostic or evaluation purposes" means services provided by a licensed physician to determine a child's developmental status and need for early intervention services..

(6) "Nursing services" includes -

(i) The assessment of health status for the purpose of providing nursing care, including the identification of patterns of human response to actual or potential health problems;

(ii) Provision of nursing care to prevent health problems, restore or improve functioning, and promote optimal health and development; and

(iii) Administration of medications, treatments, and regimens prescribed by a licensed physician.

Note 1: . . . the appropriate location of services for some infants and toddlers might be a hospital setting - during the period in which they require extensive medical intervention. However, for these and other eligible children, it is important that efforts be made to provide early intervention services in settings and facilities that do not remove the children from natural environments (e.g., the home, day care centers, or other community settings). Thus, it is recommended that services be community-based, and not isolate an eligible child or the child's family from settings or activities in which children without handicaps would participate.

Note 2: The list of services . . . is not exhaustive and may

include other types of services, such as vision services, and the provision of respite and other family support services. There also are other types of personnel who may provide services under this, including vision specialists, paraprofessionals, and parent-to-parent support personnel.

303.13 Health services.

(a) As used in this part, "health services" means services necessary to enable a child to benefit from the other early intervention services under this part during the time that the child is receiving the other early intervention services.

(b) The term includes -

(1) Such services as clean intermittent catheterization, tracheotomy care, tube feeding, the changing of dressings or osteotomy collection bags, and other health services; and,

(2) Consultation by physicians with other service providers concerning the special health care needs of eligible children that will need to be addressed in the course of providing other early intervention services.

(c) The term does not include the following:

(1) Services that are -

(i) Surgical in nature (such as cleft palate surgery, surgery for club foot, or the shunting of hydrocephalus); or,

(ii) Purely medical in nature (such as hospitalization for management of congenital heart ailments, or the prescribing of medicine or drugs for any purpose).

(2) Devices necessary to control or treat a medical condition.

(3) Medical-health services (such as immunizations and regular "well-baby" care) that are routinely recommended for all children.

Note: The definition in this section distinguishes between the health services that are required under this part, and the medical-health services that are not required. The IFSP requirements in Sub-part D provide that, to the extent appropriate, these other medical-health services are to be included in the IFSP, along with the funding sources to be used in paying for the services. Identifying these services in the IFSP does not impose an obligation to provide the services if they are otherwise not required to be provided under this part.

Comment: A number of commenters requested further guidance regarding what types of services are included as "health services."

Commenters recommended specific items and services to be added, such as (1)Presently allowable services under Part B [in reference to P.L. 94-142] (e.g., clean intermittent catheterization); (2) health management services that accompany surgical or purely medical procedures, including consultations with medical personnel; (3) prescribed devices necessary for the control or treatment of a medical condition such as ventilators and gavage equipment; and (4) services that occur during the actual time a child participates in a center-based early intervention program.

Discussion: The Secretary agrees that needed health services should be made available during the time other early intervention services are provided, so that a child can benefit from the other early intervention services. Examples of necessary health services include tracheostomy care, tube feeding, and the changing of dressings or osteotomy bags. In addition, consultation by medical providers with other early intervention personnel may be necessary, so that a child can benefit from the provision of early intervention services. However, the Secretary does not believe that the costs of medical-health services, such as immunizations and regular "well-baby" care, are allowable under this part, because they are services that are routinely recommended for all children. Through not covered under this part, these medical-health services are essential for all infants and toddlers. The Secretary believes that, to the extent appropriate, these services should be included in the IFSP, along with the funding sources to be used in paying for the services. However, the Secretary does not believe that the provision of a device necessary for the control or treatment of a medical condition can be included as health services, since the statute limits coverage of medical services to those necessary for diagnostic and evaluation purposes only.

Change: Section 303.13 has been expanded to include the following: (1) Language certifying that "health services" means those services necessary to enable a child to benefit from the other early intervention services the child is receiving under this part during the time that the child is receiving the other services; (2) examples of health services that a State is required to provide; (3) a paragraph regarding allowable consultation services; and examples of medical-health services that are not required. The note following section 303.13 has been revised to clarify that, to the extent appropriate, medical-health services are to be included in the IFSP, along with the funding sources to be used in paying for those services.

303.16 Infants and toddlers with handicaps.
(a) As used in this part, "infants and toddlers with handicaps" means individuals from birth through age two who need early intervention services because they -

(1) Are experiencing developmental delays, as measured by

appropriate diagnostic instruments and procedures in one or more of the following areas:

(i) Cognitive development;

(ii) Physical development, including vision and hearing;

(iii) Language and speech development;

(iv) Psychosocial development; or,

(v) Self-help skills; or,

(2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

(b) The term may also include, at a State's discretion, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided.

Note 1: As used in paragraph (a)(2) of this section, "high probability" is not intended to be viewed as a statistical term. Rather, the phrase "have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay" applies to conditions with known etiologies and developmental consequences. Examples of these conditions include Down Syndrome and other chromosomal abnormalities, sensory impairments, including vision and hearing, inborn errors of metabolism, microcephaly, severe attachment disorders, including failure to thrive, seizure disorders, and fetal alcohol syndrome.

Note 2: . . . Under this provision, States have the authority to define who would be "at risk of having substantial developmental delays if early intervention services are not provided." In defining the "at risk" population, States may include well-known biological and other factors that can be identified during the neonatal period, and that place infants "at risk" for developmental delay. Commonly cited factors relating to infants include low birth weight, respiratory distress as a newborn, lack of oxygen, brain hemorrhage, and infection. It should be noted that these factors do not predict the presence of a barrier to development, but they may indicate children who are at higher risk of developmental delay than children without these problems.

Sections 303.300 through 303.361 deal with specific elements of the Program and Service Components of a Statewide System of Early Intervention Services. As previously indicated, only select

aspects of certain components will be noted here as such have particular relevance to the State Title V Programs.

303.321 Comprehensive child find system.

. . .(c) Coordination. (1) The lead agency, with the assistance of the Council, shall ensure that the child find system under this part is coordinated with all other major efforts to locate and identify children conducted by other State agencies responsible for administering the various education, health, and social service programs relevant to this part, including efforts in the -

. . .(ii) Maternal and Child Health program under Title V of the Social Security Act;

(iii) Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) under Title XIX of the Social Security Act;

(iv) Developmental Disabilities Assistance and Bill of Rights Act; and

(v) Head Start Act. . .

(2) The lead agency, with the advice and assistance of the Council, shall take steps to ensure that -

(i) There will not be unnecessary duplication of effort by the various agencies involved in the State's child find system under this part; and

(ii) The State will make use of the resources available through each public agency in the State to implement the child find system in an effective manner.

(d) Referral Procedures. (1) The child find system must include procedures for use by primary referral sources for referring a child to the appropriate public agency within the system for -

(i) Evaluation and assessment in accordance with sec. 303.322 and 303.323; or

(ii) As appropriate, the provision of services, in accordance with sec. 303.342(a) or 303.345.

(2) The procedures required in paragraph (b)(1) of this section must -

(i) Provide for an effective method of making referrals by primary referral sources; and

(ii) Ensure that referrals are made no more than two working

days after a child has been identified.

(3) As used in paragraph (d)(1) of this section, "primary referral sources" includes -

(i) Hospitals, including prenatal and postnatal care facilities;

(ii) Physicians;

(iii) Parents;

(iv) Day care programs;

(v) Local educational agencies;

(vi) Public health facilities;

(vii) Other social service agencies; and,

(viii) Other health care providers.

(e) Timelines for public agencies to act on referrals. Once the public agency receives a referral, it shall, within 45 days -

(i) Complete the evaluation and assessment activities in sec. 303.322; and

(ii) Hold an IFSP meeting, in accordance with sec. 303.342.

Note: In developing the child find system under this part, States should consider (1) tracking systems based on high-risk conditions at birth, and (2) other activities that are being conducted by various agencies or organizations in the State.

300.322 Evaluation and assessment.

(a) General. (1) Each system must include the performance of a timely, comprehensive, multidisciplinary evaluation of each child, birth through age two, referred for evaluation, including assessment activities related to the child and the child's family.

(c) Evaluation and assessment of the child. The evaluation and assessment of each child must -

(1) Be conducted by personnel trained to utilize appropriate methods and procedures;

(2) Be based on informed clinical opinion; and

(3) Include the following:

(i) A review of pertinent records related to the child's current health status and medical history.

(ii) An evaluation of the child's level of functioning in each of the following developmental areas:

(A) Cognitive development.

(B) Physical development, including vision and hearing.

(C) Language and speech development.

(D) Psychosocial development.

(E) Self-help skills.

(iii) An assessment of the unique needs of the child in terms of each of the developmental areas in paragraph (c)(3)(ii) of this section, including the identification of services appropriate to meet those needs. . .

(e) Timelines. (1) . . . the evaluation and initial assessment of each child (including the family assessment) must be completed within the 45-day time period required in sec. 303.321(e).

Individualized Family Service Plans (IFSPs)
303.340 General.

. . .(3) Include services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child. . .

Lead agency responsibility. . . If there is a dispute between agencies as to who has responsibility for developing or implementing an IFSP, the lead agency shall resolve the dispute, or assign responsibility.

Note: In instances where an eligible child must have both an IFSP and an individualized service plan under another Federal program, it may be possible to develop a single consolidated document, provided that it (1) contains all of the required information in sec. 303.344, and (2) is developed in accordance with requirements of this part.

303.341 Meeting the IFSP requirements for years four and five.

(a) Fourth year requirements [about October, 1990]. No later than the beginning of the fourth year of a State's participation under this part, the State shall ensure that -

(1) Evaluations and assessments are conducted in accordance with sec. 303.322;

(2) An IFSP is developed, in accordance with sec. 303.342(a) and 303.343(a), for each child determined to be eligible under this part and the child's family; and

(3) Case management services are available to each eligible child and the child's family.

(b) Requirements for the fifth year [about October, 1991]. No later than the beginning of the fifth year of a State's participation under this part, a current IFSP must be in effect and implemented for each eligible child and the child's family.

303.342 Procedures for IFSP development, review and evaluation.

(a) Meeting to develop initial IFSP: timelines. For a child who has been evaluated for the first time and determined to be eligible, a meeting to develop the initial IFSP must be conducted within the 45 day time period in sec. 303.321(e).

Note: . . . it is necessary to have only one separate periodic review each year (i.e., six months after the initial and subsequent annual IFSP meetings), unless conditions warrant otherwise.

303.344 Content of IFSP.

(a) Information about the child's status. (1) The IFSP must include a statement of the child's present levels of physical development (including vision, hearing, and health status), cognitive development, language and speech development, psychosocial development, and self-help skills.

(b) Family information. With the concurrence of the family, the IFSP must include a statement of the family's strengths and needs related to enhancing the development of the child.

(c) Outcomes. . .

(d) Early Intervention Services. . . including - . . .

(ii) The payment arrangements, if any. . .

(e) Other services. (1) To the extent appropriate, the IFSP must include -

(i) Medical and other services that the child needs, but that are not required under this part; and

(ii) If necessary, the steps that will be undertaken to secure those services through public or private resources.

(2) The requirement in paragraph (e)(1) of this section does not apply to routine medical services (e.g., immunizations and

"well-baby" care), unless a child needs those services and the services are not otherwise available or being provided. . .

(g) Case Manager. (1) The IFSP must include the name of the case manager from the profession most immediately relevant to the child's or family's needs, who will be responsible for the implementation of the IFSP and coordination with other agencies and persons. . .

Note 2: The early intervention services in paragraph (d) of this section are those services that a State is required to provide a child in accordance with sec. 303.12. The "other services" in paragraph (e) of this section are services that a child or family needs, but are neither required nor covered under this part. While listing the non-required services in the IFSP does not mean those services must be provided, their identification can be helpful to both the child's family and the case manager, for the following reasons: First, the IFSP would provide a comprehensive picture of the child's total service needs (including the need for medical and health services, as well as early intervention services). Second, it is appropriate for the case manager to assist the family in securing the non-required services (e.g., by (1) determining if there is a public agency that could provide financial assistance, if needed, (2) assisting in the preparation of eligibility claims or insurance claims, if needed, and (3) assisting the family in seeking out and arranging for the child to receive the needed medical-health services).

Thus, to the extent appropriate, it is important for a State's procedures under this part to provide for ensuring that other needs of the child, and of the family related to enhancing the development of the child, such as medical and health needs, are considered and addressed, including determining (1) who will provide each service, and when, where, and how it will be provided, and (2) how the service will be paid for (e.g., through private insurance, an existing Federal-State funding source, such as Medicaid or EPSDT, or some other funding arrangement).

303.520 Policies related to payment for services.

(a) General. Each lead agency is responsible for establishing State policies related to how services to children eligible under this part and their families will be paid for under the State's early intervention program. The policies must - . . .

(2) Be reflected in the interagency agreements required in sec. 303.523 . . .

303.521 Fees.

(a) General. A State may establish . . . a system of payments for early intervention services, including a schedule of sliding fees.

(b) Functions not subject to fees. The following are required functions that must be carried out at public expense by a State, and for which no fees may be charged to parents:

(1) Implementing the child find requirements in sec. 303.321;

(2) Evaluation and assessment, as included in sec. 303.322, and including the functions related to evaluation and assessment in sec. 303.12.

(3) Case management, as included in sec. 303.6 and 303.344(g).

(4) Administrative and coordinative activities related to -

(i) The development, review, and evaluation of IFSPs in sec. 303.340 through 303.346; and . . .

(c) States with mandates to serve children from birth. If a State has in effect a State law requiring the provision of a free appropriate public education to children with handicaps from birth, the State may not charge parents for any services (e.g., physical or occupational therapy) required under that law that are provided to children eligible under this part and their families.

303.522 Identification and coordination of resources.

(a) Each lead agency is responsible for -

(1) The identification and coordination of all available resources for early intervention services within the State, including those from Federal, State, local, and private sources; and

(2) Updating the information on the funding sources in paragraph (a)(1) of this section, if a legislative or policy change is made under any of those sources.

(b) The Federal funding sources in paragraph (a)(1) of this section include -

(1) Title V of the Social Security Act (relating to Maternal and Child Health);

(2) Title XIX of the Social Security Act (relating to the general Medicaid Program, and EPSDT); . . .

(7) Other Federal programs.

303.523 Interagency agreements.

(a) General. Each lead agency is responsible for entering into formal interagency agreements with other State-level agencies

involved in the State's early intervention program . . .

(b) Financial responsibility. Each agreement must define the financial responsibility of the agency for paying for early intervention services (consistent with State law and the requirements of this part).

(c) Procedures for resolving disputes. (1) Each agreement must include procedures for achieving a timely resolution of intra- and interagency disputes about payments for a given service, or disputes about other matters related to the State's early intervention program. Those procedures must include a mechanism for making a final determination that is binding upon the agencies involved. . .

303.526 Policy for contracting or otherwise arranging for services.

Each system must include a policy pertaining to contracting or making other arrangements with public or private providers to provide early intervention services. . .

Note: In implementing the statewide system, States may elect to continue using agencies and individuals in both the public and private sectors that have previously been involved in providing early intervention services, so long as those agencies and individuals meet the requirements of this part.

303.527 Payor of last resort.

(a) Non-substitution of funds. Except as provided in paragraph (b)(1) of this section, funds under this part may not be used to satisfy a financial commitment for services that would otherwise have been paid for from another public or private source but for the enactment of Part H of the Act. Therefore, funds under this part may be used only for early intervention services that an eligible child needs but is not currently entitled to under any other Federal, State, local, or private source.

(b) Interim payments; reimbursement. (1) If necessary to prevent a delay in the timely provision of services to an eligible child or the child's family, funds under this part may be used to pay the provider of services, pending reimbursement from the agency or entity that has ultimate responsibility for the payment.

(2) Payments under paragraph (b)(1) of this section may be made for -

(i) early intervention services, as described in sec. 303.12;

(ii) Eligible health services (see sec.303.13); and,

(iii) Other functions and services authorized under this part, including child find, and evaluation and assessment.

(3) The provisions of paragraph (b)(1) of this section do not apply to medical services or "well-baby" health care (see sec. 303.13(c)(1).

(c) Non-reduction of benefits. Nothing in this part may be construed to permit a State to reduce medical or other assistance available or to alter eligibility under Title V of the Social Security Act (relating to Maternal and Child Health) or Title XIX of the SSA (relating to Medicaid for children eligible under this part) within the State.

Note: The Congress intended that the enactment of Part H not be construed as a license to any agency (including the lead agency and other agencies in the State) to withdraw funding for services that currently are or would be made available to eligible children but for the existence of the program under this part. Thus, the Congress intended that other funding sources would continue, and that there would be greater coordination among agencies regarding the payment of costs.

The Congress further clarified its intent concerning payments under Medicaid by including in section 411(k)(13) of the Medicare Catastrophic Coverage Act of 1988 (Pub. L. 100-360) an amendment to Title XIX of the Social Security Act. That amendment states, in effect, that nothing in this Title shall be construed as prohibiting or restricting, or authorizing the Secretary of Health and Human Services to prohibit or restrict, payment under subsection (a) for medical assistance for covered services furnished to a handicapped infant or toddler because such services are included in the child's IFSP adopted pursuant to Part H of the Education for All Handicapped Act.

303.540 Data collection.

(a) Each system must include the procedures that the State uses to compile data on the statewide system. The procedures must -

(1) Include a process for -

(i) Collecting data from various agencies and service providers in the State;

(ii) Making use of appropriate sampling methods, if sampling is permitted; . . .

300.600 Establishment of Council.

(a) A State that desires to receive financial assistance under this part shall establish a State Interagency Coordinating Council

composed of 15 members. . .

Note: The number of members on the Council was established by statute. However, to the extent that a State determines that full and effective representation requires more than 15 members, it would be appropriate for the Council to request the Governor to appoint additional members on an ex officio basis, or, with the permission of the Governor, for the Council chairperson to take that action.

In addition to appointing ex officio members to the Council, consideration might be given to establishing (1) regional committees, or (2) special committees to address key issues related to the effective implementation of this part. . .

300.601 Composition.

The Council must be composed of the following:

(a) At least -

(1) Three members who are parents of infants and toddlers with handicaps or of handicapped children aged three through six;

(2) Three public or private providers of early intervention services;

(3) One representative from the State legislature; and,

(4) One person in personnel preparation.

(b) Other members representing each of the appropriate agencies involved in the provision of or payment for early intervention services to eligible children and their families, and others selected by the Governor.

Note: In order to enhance the effectiveness of the Council in carrying out its functions under this part, it is recommended that efforts be made to include representatives of each State agency or other major service provider that has a role in the State's early intervention program, such as the state health and education departments, health care providers, and other key providers. . .

Functions of the Council
303.650 General.

Each Council shall -

(a) Advise and assist the lead agency in the development and implementation of the policies that constitute the statewide system;

(b) Assist the lead agency in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the State;

(c) Assist the lead agency in the effective implementation of the statewide system, by establishing a process that includes -

(1) Seeking information from service providers, case managers, parents, and others about any Federal, State, or local policies that impede timely service delivery; and

(2) Taking steps to ensure that any policy problems identified under paragraph (c)(1) of this section are resolved; and

(d) To the extent appropriate, assist the lead agency in the resolution of disputes.

III. OPPORTUNITIES FOR STATE TITLE V PROGRAMS

Hopefully, the general relevance of these regulations to State Title V Programs is obvious to MCH and CSHCN program staff. In the following section, select necessary components of a state system are used as points of reference to identify some of the major opportunities for involvement by State Title V Programs in the development and implementation of P.L. 99-457, Part H. For illustrative purposes, experiences related to the planning of the Infants and Toddlers Program in Maryland will be cited, where appropriate, as staff from the Maryland State MCH and CSHCN Programs have and continue to play an integral role its development and implementation. This discussion also builds on the Report of a work group convened in Washington, D.C. in early 1988.

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Continuity of Care for At-Risk Infants and Their Families: Opportunities for Maternal and Child Health Programs and Programs for Children with Special Health Needs.

Report of a work group convened by the Bureau of Maternal and Child Health and Resources Development and facilitated by The National Center for Clinical Infant Programs, February 1988.

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State Definition of Developmental Delay

Each state must determine the definition of "developmental delay" that will be used by that state to carry out the program under Part H. Recognizing that standardized measures may not be appropriate for a given age or developmental area, states are required to ensure that informed clinical opinion is used in determining a child's eligibility for early intervention services. For example, the Maryland State Interagency Coordinating Council

(ICC) has adopted the following definition:

The term 'infants and toddlers with handicaps' means children from birth through age two who shall be eligible for early intervention services, as determined by a multidisciplinary team, and documented by a qualified examiner, because they:

a. Are experiencing developmental delays or disordered behavior, as measured and verified by appropriate diagnostic instruments and procedures indicating that the child is functioning at least 25% below his or her chronological age in one or more of the following developmental areas:

(1) cognitive development,

(2) physical development, including fine and gross motor, and sensory development,

(3) speech and language development,

(4) psychosocial development,

(5) self-help skills; or,

b. Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay (e.g., children with sensory impairments, inborn errors of metabolism, microcephaly, fetal alcohol syndrome, epilepsy, and Down syndrome and other chromosomal abnormalities); or,

c. Manifest atypical development or behavior, which is demonstrated by abnormal quality of performance and function in one or more of the above specified developmental areas, interferes with current development, and is likely to result in subsequent delay (even when developmental assessment does not document a 25% deficit).

State and private health agency staff in Maryland played a key role in advocating for and clarifying the "atypical" criteria. Informed clinical opinion will be essential in determining a child's eligibility under this section. A number of state health departments are promoting the adoption of an even broader definition of eligibility to include "at risk" infants and toddlers and their families. In Maryland, for example, an "at-risk" child

is one who "currently demonstrates no abnormality in any developmental area, but has either biological or environmental factors that increase the probability of developmental delay in the future." The ICC in Maryland has recommended offering tracking and monitoring, parent training, and case management for the "at-risk" population on a pilot basis for a three year period, beginning in 1992, in order to obtain actual numbers of infants and toddlers that would be involved in such a system. This would be limited to select jurisdictions, to include urban, suburban and rural areas.

Such an undertaking will provide the opportunity to deal with a more limited population, as defined by Maryland's definition of "developmental delay," prior to offering select early intervention services to the less well-defined, both in terms of eligibility criteria and service needs, environmental and biologic risk populations. This delayed effort in no way implies that the existing service system, particularly the State MCH Program, will not continue to give priority attention to at-risk populations.

Even if a State decides on a more restricted definition of eligibility for services under P.L. 99-457, the process of arriving at a definition, which involves Title V Program staff, can stimulate discussion of how to address the needs of those who remain unserved. Health professionals can provide a critical perspective of the advantages and the uncertainties of early risk identification and the importance of multivariate considerations in determining risk status. They can also reinforce the importance of primary health care for all children and of a "medical home" for

each child, including those with chronic conditions.

Central Directory

The Department of Health and Human Services administers twelve programs that are potential resources to states in contributing to comprehensive early intervention services. These 12 programs include:

- Maternal and Child Health Block Grants, authorized by the Social Security Act,
- Head Start Program, authorized by the Head Start Act,
- Medicaid, authorized by the Social Security Act,
- Child Welfare Services Program, authorized by the Social Security Act,
- Developmental Disabilities Basic State Grants Program, authorized by the Developmental Disabilities Assistance and Bill of Rights act,
- Alcohol, Drug Abuse and Mental Health Block Grant Program, authorized by the Public Health Services Act,
- Community Health Service Program, authorized by the Public Health Service Act,
- Indian Health Service Program, authorized by the Indian Health Care Improvement Act,
- Migrant Health Services Program, authorized by the Public Health Services Act,
- Preventative Health and Health Services Block Grant, authorized by the Public Health Service Act,
- Health Care for the Homeless Program, authorized by the Homeless Assistance Act, and,
- Social Services Block Grant, authorized by the Social Security Act.

These Programs reflect a broad array of eligibility criteria and allow varying degrees of State discretion in establishing service priorities and populations served, as well as in funding

approaches. These Programs were never designed to be component parts of a statewide, comprehensive early intervention system as they have diverse human service and political objectives underlying their various authorization statutes. They were designed to be programmatically and politically responsive to a broad array of special populations and human service needs.

As none of these Programs have early intervention services as their central focus, a complex coordination task is required of the state agencies in developing a central directory of early intervention services. The State Title V Programs have an integral role to play in this task, as well as in describing available primary and specialized health care services available through the complex private delivery system in the state. Without this involvement, there is the risk that medical and health resources, both public and private, may be under-represented in the central directory of services.

Comprehensive Child Find System

It should be emphasized that the "child find system" referred to within P.L. 99-457 is not synonymous with "Child Find" under P.L. 94-142, which is primarily a state and local education agency responsibility. The latter is but one of the major components of the "child find system" under this part. Other required components of the system include resources and efforts available through the State Title V Programs and through Early Periodic Screening, Diagnosis and Treatment (EPSDT) activities.

Since virtually all children are seen in health care

facilities, at least at the time of delivery, health professionals must be integrally involved in the design and implementation of child find initiatives. As indicated in the Regulations, primary referral sources for referring a child to the appropriate resource within the early intervention system for evaluation and assessment includes hospitals, health care clinics, physicians, public health facilities and other health care providers. The ambitious mandate that "referrals are made no more than two working days after a child has been identified" by primary referral sources will require a high level of collaboration between primary referral sources, particularly those in the private sector, and the public health components (i.e., State Title V Programs) of the early intervention system.

It is noteworthy that the term "screening" is not mentioned in the Final Regulations for Part H. However, it should be understood that screening procedures, both formal (i.e., Denver Developmental Screening Test) and informal, will continue to be the basis upon which many primary referral sources make decisions regarding a child's need for referral to evaluation/assessment services under Part H.

Evaluation and Assessment

Under this section, evaluation to determine a child's initial and continuing eligibility consistent with the state's definition of "infants and toddlers with handicaps" and assessment to identify a child and family's strengths and needs must be multidisciplinary in nature. Although the differentiation of the terms "evaluation"

and "assessment" is somewhat artificial within the context of actual clinical practice, it does serve to emphasize that the identification of a child's deficits is only the first step in the process.

As used in the Regulations, "multidisciplinary" means the involvement of two or more disciplines or professions. State Title V Programs have a long history of multi- and interdisciplinary efforts, particularly in the comprehensive evaluation/assessment of children and families. For example, in Maryland, as in most states, the Program for Children with Special Health Care Needs supports a Statewide network of tertiary center and community-based diagnostic and evaluation specialty clinics. These resources must be integral components of the conceptual model for evaluation/ assessment being developed in each state under Part H.

This network offers the possibility of using an existing Statewide service delivery framework, in collaboration of course with other programs/agencies, to meet the requirement under this part, particularly the requirements for "informed clinical opinion" and review of health status and medical history. Recognizing that its clinic network has traditionally served predominantly preschool and school-aged children, the Maryland Children's Medical Services has recently undertaken a review of its local health department-based clinics and tertiary-based specialty clinics. The purpose of this review is to determine the Statewide capacity of this network related to the neuro-developmental evaluation/assessment of infants and toddlers and to provide technical and program

assistance in strengthening this capability. Although the current network is considered to be multidisciplinary (i.e. Medicine, Nursing, Psychology, Social Work), more focused efforts directed at infants and toddlers will require an expansion of the team to include other health related professionals (i.e., physical, occupational and speech/language therapists) and a more integral role for early education personnel.

Another Title V related Program network that has served as a model of interdisciplinary evaluation/assessment services and training throughout the nation is the University Affiliated Programs (UAP). In Maryland, faculty and staff from the Johns Hopkins University affiliated UAP, the Kennedy Institute, are playing an active role in both State and local efforts toward a Statewide Early Intervention System and demonstrate the important role of private providers. In fact, a senior faculty member based at the Kennedy Institute is the current Chairperson of the Interagency Coordinating Committee.

Individualized Family Service Plans (IFSPs) and Case Management

Since service coordination or case management is closely linked to the development and implementation of an IFSP, this part represents, perhaps, the cornerstone of P.L. 99-457. The IFSP, as a written document itself, is an important planning and evaluation tool. More importantly however, it should represent a process of interaction, collaboration and partnership between families and professionals whereby there is a "coming together" of concerned individuals to do what is best for a young child with specialized

needs in the context of his/her family and community. The following resource document, available through the Association for the Care of Children's Health in Washington, D.C., suggests a philosophy and conceptual framework for the IFSP and provides recommendations for practices and procedures that are consistent with state-of-the-art, family-centered early intervention.

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Guidelines and Recommended Practices for the Individualized Family Service Plan. Prepared by the National Early Childhood Technical Assistance System (NEC*TAS) and the Association for the Care of Children's Health, March 1989.

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The IFSP should provide a comprehensive picture of the child and family's total service needs, including medical services (i.e., purely medical or surgical in nature - e.g., hospitalization for the management of congenital heart disease, cleft palate surgery) and other health services that are not defined under P.L. 99-457 as "early intervention services." However, it is important for public health professionals to understand that identifying these services in the IFSP does not impose an obligation under this law to provide the services if they are not otherwise required to be provided under sections 303.12 (d)(4)&(5) and 303.13 of the Final Regulations. Thus, the entitlement aspect of P.L. 99-457 falls short of assuring that an infant or toddler's total needs, particularly certain medical and health needs, will be met under public supervision and at no cost to the family. However, the steps that will be taken to access such services through public or private providers must be specified in the IFSP.

The provision in the Regulations that the case manager should be from the profession that is most immediately relevant to the child's or family's needs can be interpreted quite broadly. The State CSHCN Program must play a role in providing and/or assuring that children with special health care needs and their families, particularly those who require complex medical/health management regimes, have access to the case management services of professionals sensitive to the complex management issues of such children.

Until recently, there has not been a Federal legal mandate requiring case management services for children with special health care needs. However, State Programs for Children with Special Health Care Needs have traditionally provided some form of service coordination, particularly in assisting families to access services. In many State Programs the provision of case management services could best be characterized as more system-centered in nature. A system-centered role for a case manager in a health department-based program, for example, may be to determine eligibility for the program's services, identify needs as they relate to services provided by the program, arrange for such services and maintain records to fulfill the program's reporting requirements.

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The Title V State Programs and the Provision of Case Management Services for Children with Special Health Care Needs and Community-Based Case Management Programs for Children with Special Health Care Needs. National Maternal and Child Health Resource Center, College of Law Building, University of Iowa, Iowa City, Iowa 52242, Phone: (319) 335-9046.

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The Supplemental Security Income/Disabled Children's Program (SSI/DCP) was a federally funded Program under Section 1615 of the Social Security Act as amended by P.L. 95-566 requiring cooperative agreements among State agencies which provide services to children with disabilities receiving SSI benefits. Essentially, this Program provided referral by the Social Security Administration of blind or disabled SSI recipients under 16 years of age to a designated State agency, which was most often the State Crippled Children's Program. This designated State agency was responsible for the administration of a State plan which provided for counseling, establishment and monitoring of Individual Service Plans (ISP), and service referrals and coordination.

Although the specific requirements of this legislation were rescinded by the Omnibus Budget Reconciliation Act of 1981, the experience of State Title V Programs with the SSI/DC Program represents a useful resource to states in their planning efforts under Part H. A review of the 1979 Federal Regulations under which the SSI/DC Program operated (Referral and Services for Blind and Disabled Children Receiving Supplemental Security Income Benefits, 42 CFR Part 51a) indicates many similarities to the intent and requirements under Part H. For example, there was a recognition that the ability of the designated State agency and other agencies to carry out the ISP is subject to the various limitations of these agencies, including financial and staff resources. Thus, it was expected that cooperative interagency arrangements would be developed.

The specific requirements pertaining to the establishment of an ISP were quite consistent with those for an IFSP under Part H, including the participation of parents, consideration of the comprehensive needs of the child, designation of a program coordinator responsible for ensuring the implementation of the ISP, and coordination with other Federally supported programs resulting in other individual service plans for the child (i.e., Individual Education Plan under P.L. 94-142). Under the SSI/DC Program, an array of 20 types of services were identified demonstrating the intended comprehensiveness of this Program.

As previously discussed, P.L. 99-509 required State Title V block grant agencies to use earmarked funds allotted under Section 502(c)(2)(C-D) of the Social Security Act for two purposes - "to develop primary health services demonstration programs and projects for children and to promote the development of community-based service networks and case management services for children with special health care needs." In recent guidance from the Bureau of MCH and Resources Development, it was clarified that since the statute links these two activities with the term "and," both activities - primary health programs and projects and community-based service networks and case management services for children with special health care needs - must receive earmarked financial support within each state.

Recognizing the limited funds available to states under this earmark, the Federal guidance indicates that the prescribed activities could be addressed through two approaches - a model or

pilot program with a limited population and/or geographic focus, or through combining activities funded by the earmark with larger efforts involving the "regular" block grant funds. Community-based service network/case management activities should be reported on, and the funds accounted for, in an identifiable way in both the annual RIE/Statement of Assurances and the Annual Report.

Comprehensive System of Personnel Development

The role of State Title V Program personnel in planning, developing, coordinating and evaluating, or otherwise participating in, activities/programs to assure the provision of pre-service and in-service training to medical, health and other multidisciplinary personnel is evident. Perhaps nowhere else is this opportunity greater than in collaboration with University Affiliated Programs, (UAPs) which have as their primary training mission to assist in improving the quality of local and state service systems within their respective regions.

An example of such a collaboration is the Specialized Health Needs Interagency Collaboration (SHNIC), a statewide technical assistance program to assist school, related services and early intervention personnel in managing the specialized health needs of children, including infants and toddlers, within educational and community-based program settings. This Program is a collaborative effort of the Division of Special Education (Maryland State Department of Education), the Developmental Disabilities Administration and Children's Medical Services - the State Program for CSHCN (Department of Health and Mental Hygiene) with the

Kennedy Institute (UAP).

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Sciarillo WG, Draper S, Green P, Burkett K & Demetrides S (1988). Children with Specialized Health Needs in the Special Education Setting: A Statewide Technical Assistance Approach. Infants and Young Children, 1(2):74-84.

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Another example of such a collaboration is Project Copernicus: Promoting the Practice of Family-Centered Care. The intent of this recently funded SPRANS project is to assist families and professional providers in Maryland and Virginia, through a training/consultation process, in establishing and enhancing family-centered care planning/service coordination approaches. This three-year demonstration project is a dual-State initiative that represents the collaboration of Children's Medical Services in Maryland with the Children's Specialty Services in Virginia and the Kennedy Institute UAP.

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For more information about Project Copernicus** contact: Larry Edelman, Project Coordinator, at the Kennedy Institute, 2911 E. Biddle Street, Baltimore, Maryland 21213, Phone: (301)550-9140.

**Copernicus came along and made a startling reversal - he put the sun rather than the Earth in the center of the universe. Let's pause to consider what would happen if we had a Copernican Revolution in the field of disability: the family is the center of the universe and the service delivery system is one of the many planets revolving around it. This is not a semantic exercise - such a revolution leads us to a new set of assumptions and a new vista of options for service.

- Ann P. Turnbull and Jean Ann Summers, 1987

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Another valuable Title V supported resource that must not be overlooked in the area of personnel development, both at the pre-service and in-service levels, is the nation-wide network of public health schools. These university-based facilities have particular

expertise in the science of program planning and evaluation, particularly with respect to quantitative skills development. PIC-III is certainly an excellent example of such a resource. It is noteworthy that in Maryland, a research/data analyst in the Governor's Office for Children, Youth and Families, the State's lead agency for Part H, also holds a faculty appointment in the Maternal and Child Health Department at the School of Hygiene and Public Health, The Johns Hopkins University.

Policies and Procedures Related to Financial Matters

As explicitly stated in the Final Regulations, identification and coordination of all available resources for early intervention services within the State is required, including Title V relating to Maternal and Child Health and Children with Special Health Care Needs Programs and Title XIX relating to the general Medicaid Program and to EPSDT. The limited Federal funds made available to states through P.L. 99-457 are under a "payor of last resort" or non-supplanting provision. For example, a State is not permitted to reduce medical/health or other benefits available or to alter eligibility under Title V or Title XIX within the State. Thus, the State Title V Programs must participate in the planning under this section.

State Title V Programs have a wealth of experience in contracting or facilitating care through community- and tertiary-based public and private providers in meeting the comprehensive health and habilitative needs of children and families. Additionally, in collaboration with State Medicaid

Programs through the Home and Community-Based Waivers, State CSHCN Programs have demonstrated innovative solutions to complex service delivery problems related to children who are technology dependent.

It is beyond the scope of this report to discuss the many and complex funding issues inherent in serving children with specialized health and developmental needs, or to identify the funding strategies/opportunities in this area. This has been the focus of other available resource documents.

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Funding Care Coordination Services for Families of Children with Special Health Care Needs. Authored by C.L. Gaylord and A.L. Levy, and published by the Center for Public Representation, 520 University Avenue, Madison, WI, 53703, Phone: (608)251-4008.

Health Care Coverage for the Child with a Chronic Illness or Disability. Authored by C.L. Gaylord and A.M. Leonard, and published by the Center for Public Health Representation.

Medicaid Financing for Early Intervention Services. Authored by H.B. Fox and R. Yoshpe and available through the National Center for Networking Community Based Services, Georgetown University Child Development Center, 3615 Wisconsin Ave., N.W., Washington, D.C., Phone: (202)687-8635.

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Coordinating funding for early intervention services from federal, state, local and private sources will be one of the major challenges for states. Under Part H, medical services for diagnostic and evaluation purposes in order to determine a child's developmental status and need for early intervention, and health services necessary to enable a child to benefit from the other early intervention services are considered entitlement services. However, it is intended that the state Part H program is the "payor of last resort" for such medical/health related services. Financing

should be provided first through private insurance, Medicaid and EPSDT, and Title V and other public health care sources, in that order.

Fortunately, there is considerable overlap between the services authorized under the general Medicaid statute, including EPSDT, and the medical/health related services mandated under Part H. Additionally, Federal statute changes made by the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) (P.L. 99-272) provide each state with the option of amending its state Medicaid plan to offer case management for a targeted population as a reimbursable service. Under COBRA, case management services are not limited to services needed to coordinate only Medicaid covered services, rather case management services means "services which will assist individuals eligible, under the plan [Medicaid] in gaining access to needed medical, social, educational, and other services."

"Targeting" may be based upon age, type or degree of disability or condition, or any other identifiable characteristic or combination of characteristics. The state is also permitted to make targeted case management services available to geographically limited portions of the state. In Maryland, for example, the Stated Part H Program is pursuing this option, in collaboration with the State Medicaid Office, for infants and toddlers eligible under Part H who are not receiving reimbursable case management services through another source (i.e., participants in the Medicaid waiver program). Also, the Children's Medical Services Program is

exploring the feasibility of expanding case management services to children, including infants and toddlers, receiving Supplemental Security Income (SSI) benefits and who have complex medical and developmental needs through this option.

As previously discussed, Part H contains a "supplement, not supplant" provision, whereby "Nothing in this part shall be construed to permit the State to reduce medical or other assistance available or to alter eligibility under Title V of the Social Security Act (relating to maternal and child health) or Title XIX of the Social Security Act (relating to Medicaid for handicapped infants and toddlers) within the State." The Medicare Catastrophic Coverage Act of 1988, P.L. 100-360, contains a significant amendment to the Social Security Act pertaining to the financing of services included in a child's Individual Education Plan (IEP) or an infant, toddler and their families' Individualized Family Service Plan (IFSP). According to the amendment, Medicaid reimbursement can not be restricted or prohibited for covered services because the services are included in an IEP or an IFSP. This change has significant implications for interagency collaboration between health and education in the financing and monitoring of services for children with disabilities.

Data Collection

In view of the goal of PIC-III to increase states' capacity to effectively utilize data for needs assessment, program planning and monitoring, and outcome evaluation, particular attention will be given to this area. The Final Regulations for Part H specify

the following requirements under this part:

303.540 Data Collection.

(a) Each system must include the procedures that the State uses to compile data on the statewide system. The procedures must -

(1) include a process for -

(i) Collecting data from various agencies and service providers in the State;

(ii) Making use of appropriate sampling methods, if sampling is permitted; and

(iii) Describing the sampling methods used, if reporting to the Secretary; and

(2) Provide for reporting the data required under section 676(b)(14)* of the Act, and other information that the Secretary may require, including information required under section 618** of the Act.

(b) The information required in paragraph (a)(2) of this section must be provided at the time and in the manner specified by the Secretary.

* **Sec. 676(b)(14)** a system for compiling data on the number of handicapped infants and toddlers and their families in the State in need of appropriate early intervention services (which may be based on a sampling of data), the number of such infants and toddlers and their families served, the types of services provided (which may be based on a sampling of data), and other information required by the Secretary.

** **Sec. 618(a)** The Secretary shall directly or by grant, contract, or cooperative agreement, collect data and conduct studies, investigations, and evaluations - (1) to assess progress in the implementation of this Act, the impact, and the effectiveness of State and local efforts . . . to provide . . . early intervention services to handicapped and infants and toddlers, . . .

** **Sec. 618(b)** . . . shall obtain data concerning programs and projects assisted under this Act and under other Federal laws relating to handicapped infants, toddlers . . . including,

(1) the number of handicapped infants, toddlers . . . receiving . . . early intervention services . . . by disability category, . . .

(4) the amount of Federal, State and local funds expended in

each State specifically . . . for early intervention services (which may be based upon a sampling of data from State agencies including State and local educational agencies),

(5) the number and type of personnel that are employed in the provision of . . . early intervention services to handicapped infants and toddlers by disability category served, and the estimated number and type of additional personnel by disability category needed to adequately carry out the policy established by this Act, . . .

** Sec. 618 (d)(1) The Secretary may enter into cooperative agreements with State educational agencies and other State agencies to carry out studies to assess the impact and effectiveness of programs assisted under this Act.

(2) An agreement under paragraph (1) shall -

(A) provide for the payment of not to exceed 60 percent of the total cost of studies conducted by a participating State agency to assess the impact and effectiveness of programs assisted under this Act, and

(B) be developed in consultation with the State Advisory Panel established under this Act, the local educational agencies, and others involved in or concerned with the . . . provision of early intervention services to handicapped infants and toddlers.

(3) The Secretary shall provide technical assistance to participating State agencies in the implementation of study design, analysis, and reporting procedures. . .

As specified in the statute, state agencies with reporting requirements under this Section include . . . "Developmental Disabilities Programs, Crippled Children's Services, Mental Health/Mental Retardation Agency, and State child-development centers and private agencies under contract with local schools."

Comment: A number of commenters requested that the data collection requirements in the final regulations be more specific. Several commenters stated that a requirement should be added regarding the collection of information on the location in which early intervention services are delivered.

Discussion: The Secretary believes that sec. 303.540, which requires the lead agency to provide data required under section 618 and section 676(b)(14) of the Act and such other information

as the Secretary may require, provides sufficient authority for the Secretary to collect information on the location of services. However, he believes that the most appropriate place for providing detailed information and guidance about data requirements under this part would be in the reporting forms and instructions, and not in these final regulations.

Change: No change has been made in response to the comments. A technical change has been made by cross referencing the requirements in section 676(b)(14) of the Act instead of listing them in the regulations.

As part of its planning and development effort in preparation for the implementation of a Statewide early intervention system in October, 1990, the Maryland Infants and Toddlers Program has developed a computerized data collection system. This MacIntosh-based system is currently installed in the model demonstration projects, covering nine local jurisdictions, and will be installed in the remaining 15 jurisdictions throughout the State over the next several months. The site of installation is often the identified lead agency for each jurisdiction which is the Local Health Department in 50 percent of the sites.

When this network is fully operational, data needed to complete the federal reporting requirements will be able to be extracted from local systems and transferred to the Maryland Infants and Toddlers Program for analysis. Given the interagency nature of the required reporting system, both among local agencies and between the local and State lead agency sites, this part of the State program may serve as a paradigm for the integration of information among local and state agencies related to vulnerable children of all ages. Thus, the State Title V Programs should take particular interest in this required component of the statute.

Currently, all states are being asked by the Federal Office of Special Education and Rehabilitative Services to submit unduplicated counts of eligible infants and toddlers (according to each state's eligibility criteria) receiving early intervention services as defined by the Federal Regulations, the types of services provided, and other related information in advance of the October, 1990, implementation date. In Maryland, the Health, Education and Social Services agencies in each jurisdiction have been requested to submit an estimated count of the number of children served by service type (e.g., diagnostic and evaluative medical services), percentages of children served in various settings (e.g., agency-based, home), percentages of children in various transportation categories (e.g., program arranges transportation for family using community resources), percentages of children in various health insurance categories (e.g., Private, Children's Medical Services), and information pertaining to the numbers and types of various early intervention service personnel and to the amount of funds expended by public agencies for early intervention services.

In subsequent years, local agencies will report data to the local lead agency which is responsible for the administration of the Local Planning Grant. This local lead agency will in turn report to the Maryland Infants and Toddlers Program. The State Title V Programs should ensure that they are active participants in this data reporting loop.

Relevant to all components of the Statewide early intervention

system in Maryland, the State MCH and CSHCN Programs are currently involved with the following interagency efforts:

- The Director of the Infant, Child and Adolescent Health Program is a member of the ICC, and is Chairperson of the Service Delivery System Subcommittee of the ICC.

- The Director of the Children's Medical Services Program is an ex officio member of the ICC.

- Designated staff persons from each of these Programs provide in-kind support to the Maryland Infants and Toddlers Program, including participation in a variety of Subcommittees and Task Forces, and serve as members of the State Technical Assistance Team to the Local Planning Grant process.

- A Department of Health and Mental Hygiene work group has been developed to assure inter-Program coordination within the Department with other State agencies. The work group includes representation from the following Programs/Administrations: Infant, Child and Adolescent Health, Children's Medical Services, Hereditary Disorders, Maternal Health and Family Planning, Local Program Services, and WIC (Local and Family Health Administration); Developmental Disabilities Administration; Policy and Health Statistics, and Medicaid (Health Systems Financing Administration); Mental Hygiene Administration; and AIDS Administration.

IV. HEALTH AND MEDICAL SERVICES UNDER PART H

Although comprehensive in its intent, P.L. 99-457 does not fully address the spectrum of health and medical needs of young children at risk for or having disabilities, particularly those with special health care needs. State Title V Programs must recognize that although this legislation can complement the essential components of a comprehensive approach to the health and medical care of young children, it is limited in assuring access to a continuum of different levels of health/medical care: Level I - a medical "home," Level II - community-based hospital/clinic care, and Level III - tertiary care medical centers. Community-based care must be linked with tertiary specialty care under Part H. State Title V Programs should provide leadership in developing more effective relationships between community-based providers, including non-medical/health providers, and those providing highly specialized care in tertiary centers.

Although "health services" and "medical services only for evaluation and diagnostic purposes," as defined in the regulations, are mandated "early intervention services," they do not include:

(1) Services that are -

(i) Surgical in nature (such as cleft palate surgery, surgery for club foot, or the shunting of hydrocephalus); or,

(ii) Purely medical in nature (such as hospitalization for management of congenital heart ailments, or the prescribing of medicine or drugs for any purpose).

(2) Devices necessary to control or treat a medical condition.

(3) Medical-health services (such as immunizations and regular "well-baby" care) that are routinely recommended for all children.

As clarified in the "Note" to sec. 303.13, ". . . these other medical-health services are to be included in the IFSP, along with the funding sources to be used in paying for the services. Identifying these services in the IFSP does not impose an obligation to provide the services if they are otherwise not required to be provided under this part." Nor are these "other medical-health services" entitled through other legislative channels, as evidenced by the lack of Federal regulatory requirements to the Title V MCH Block Grant statute. Nevertheless, Part H provides states with an opportunity to forge ahead in developing an early childhood system that brings together health/medical, educational, developmental, social and other services in ways that promote a cooperative utilization of resources to do what is best for young children and their families.

A recent publication, "Establishing a Medical Home for Children Served by Part H of Public Law 99-457," emphasizes the importance of assuring a medical home for young children with developmental delays and outlines responsibilities of Title V Programs and primary health care providers toward this end.

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Establishing A Medical Home For Children Served By Part H of Public Law 99-457. An Issue Paper by the Bureau of Maternal and Child Health and Resources Development and the American Academy of Pediatrics, 1989.

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As outlined in this publication, the responsibilities of the State Title V Agency in this regard include the following:

- Coordination and facilitation of the overall system, which promotes family-centered, community-based, coordinated care for children with special health care needs and facilitates building

systems of services for these children and their families. (It is especially important to realize that children eligible for Public Law 99-457 make up only a percentage of those children who require this system/approach.)

- Alterations in the organization and in the policies of the state program for Children with Special Health Care Needs to assure that within the concept of family-centered, community-based, coordinated services the children served by Public Law 99-457 have access to a medical home or to a similar care arrangement.

- Participation in, or cooperation with, the state Interagency Coordinating Council in the design of the state Public Law 99-457, Part H plan.

- Development of funding requests for the legislature to enhance Public Law 99-457 funding as well as funding for all children with special health care needs.

- Development of financing strategies for third party reimbursement from Medicaid and private insurance to ensure and enhance adequate health care financing including payments to primary care providers for all services that they provide especially those that are related to the IFSP plan development.

- Development of referral mechanisms appropriate for both the medical home physician and the family.

- Participation in coordinating training for all professionals at critical points in the system.

- All infants and toddlers, as well as all children, must have an appropriate medical/health assessment, even if the primary problem is not health related. This will assure that an underlying medical/health issue does not compromise, or even conflict with, the early intervention services to be provided.

Again reproducing directly from this document, the clinical competencies required of medical home providers [although the term "physicians" is used throughout, this publication is relevant to other primary health care providers such as nurse practitioners] include the following:

They must have the ability to develop the concept of a family-centered plan of services by participating in the generation

of the IFSP, self-selecting their personal degree of involvement in the child's medical care and clearly communicating that degree of involvement to the parents or care-givers.

They must have the capacity to define and arrange for all medical-health consultations required for the child's assessment, and function as the coordinator or liaison to the IFSP team regarding the child's plan of health, medical, and developmental services. These abilities require communication to occur in a "two way" direction both from the child's medical home and back to the child's medical home.

An insightful commentary on the role of health services agencies related to the care of children with disabilities under P.L. 99-142 and P.L. 99-457 is provided by Saro Palmeri, M.D., of the Yale Child Development Center and Connecticut Department of Health Services. Dr. Palmeri applauds the interagency design of Part H in, " . . . inviting clinical and medical-developmental contributions . . . [as] the desired educational objectives may not be achieved without comprehensively addressing health and social issues in concert with community-based and family-centered resources". (p.205)

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Palmeri S. Public Laws and Handicapped Children. Developmental and Behavioral Pediatrics, 1989, 10(4), 205.

Another useful health-oriented perspective is provided in the following resource:

DeGraw C, Edell D, Ellers B, Hillemeier M, Liebman J, Perry C and Palfrey JS. Public Law 99-457: New opportunities to serve young children with special needs. Journal of Pediatrics, 1988, 113(6), 971-974.

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V. SURVEY OF STATE TITLE V PROGRAM ROLES RELATED TO PART H

Recognizing that planning and implementation efforts to deliver early intervention services through the provisions of Part H provides many opportunities to promote and expand collaborative relationships between State Title V and other human services programs, the Association of MCH Programs (AMCHP) undertook a survey in 1988 to demonstrate the active involvement of the Title V MCH and CSHCN programs. As the survey indicated, fifteen states reported that the health agency was designated as the lead agency for the 99-457 program. Forty-one states (79%) reported that the Title V program was represented on the Interagency Council required by P.L. 99-457 through the participation of either MCH or CSHCN program staff, or both.

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Caring for Mothers and Children: A Report of a Survey of FY 1987 State MCH Program Activities. Association of Maternal and Child Health Programs, March, 1989. Copies are available from: The National MCH Clearinghouse, 38th and R Streets, N.W., Washington, D.C., 20057, Phone: (202) 625-8410.

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The responsibilities of the lead agency for the overall administration, supervision and monitoring of the early intervention system are specified in the Federal Regulations. A recent survey (August, 1989) by the National Early Childhood Technical Assistance System (NEC*TAS), identified 17 States with the health agency as the lead agency under Part H. These States are as follows:

Alaska, Section of Maternal and Child Health, Department of Health and Human Services

American Samoa, Department of Health

Hawaii, Crippled Children Services Branch, Department of Health

Idaho, Bureau of Developmental Disabilities, Department of Health and Welfare

Kansas, State Department of Health and Environment

Massachusetts, Division of Early Childhood, Department of Public Health

Mississippi, State Board of Health

New Mexico, Department of Health and Environment

New York, State Department of Health

Ohio, State Department of Health

Puerto Rico, Department of Health

South Carolina, Department of Health and Environmental Control

Utah, Handicapped Children's Services, Division of Family Health Services

Virgin Islands, Division of Maternal and Child Health/Crippled Children's Services, Department of Health

West Virginia, Department of Health and Human Resources

Wisconsin, Department of Health and Social Services

Wyoming, Department of Health and Social Services

On the other hand, the lead agency designation in the Region III States represents a diversity of agency types as indicated in the following section. The reported amounts of Fiscal Year 1989 Part H funds allocated to each State (based upon their total infant and toddler population) as estimated by the Office for Special Education Programs is also listed.

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Region III Lead Agencies

Delaware
Infants and Toddlers Program
Exceptional Children/Special Programs Division
Department of Public Instruction
Townsent Building
P.O. Box 1402
Dover, DE 19903
(302)736-4667

FY89: $341,396

District of Columbia
Office of Early Childhood Development
Department of Human Services
609 H Street, N.E., 4th Floor
Washington, DC 20002
(202)727-1839

FY89: $341,396

Maryland
Infants and Toddlers Program
Special Secretary for Children, Youth and Families
118 N. Howard Street, Suite 608
Baltimore, MD 21201
(301)333-8100

FY89: $1,204,938

Pennsylvania
Division of Policy Development and Program Support
and Division of Community Program Development
Office of Mental Retardation
Health and Welfare Building, Room 302
Harrisburg, PA 17120
(717)783-5764

FY89: $2,795,694

Virginia
Mental Retardation, Children and Youth Services
Department of Mental Health, Mental Retardation
and Substance Abuse Services
P.O. Box 1797
Richmond, VA 23233
(804)786-3710

FY89: $1,525,464

West Virginia
Office of Behavioral Health Services
Division of Health
Department of Health and Human Resources
1800 Washington Street, East
State Capital Complex
Building 3, Room 462
Charleston, WV 25305
(304)348-0627

FY89: $403,625
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In comparison to those states in which the Title V MCH/CSHCN Program is within the Lead Agency, the implications of Part H for those states in which it is not is less clear although, as indicated previously, the Final Regulations do make specific reference on a number of occasions to the State Title V Programs. In these States particularly, the MCH and CSHCN Directors need to take a proactive role in assuring the participation of their Programs in the statewide planning and implementation of the early intervention system.

A recent national survey was conducted by the Carolina Policy Studies Program in an attempt to determine the progress that states have made in the areas of policy development, policy approval and policy implementation with regard to the fourteen required components in Part H of P.L. 99-457. Results of this study indicate:

*Every state has made some progress in several of the 14 components. States ranged from making progress on as few as 7 of the 14 components to progress on all 14 components.

*States have made more progress in policy development than in policy approval or implementation.

*The area of policy development in which the most progress was reported was "definition of developmentally delayed".

*The areas of least progress related to financial issues and interagency coordination.

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States' Progress Related to Fourteen Components of PL 99-457, Part H. Authored by G Harbin, JJ Gallagher and T Lillie, Carolina Institute for Child and Family Policy, University of North Carolina at Chapel Hill, 1989.[Carolina Policy Studies Program, 300 NCNB Plaza, Chapel Hill, NC, 27514]

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VI. CONCLUSION

Although this Report has focused on the role of State Title V Programs with respect to the planning and implementation of Part H, it should be recognized that the state agency's enabling role is operationalized, in large part, at the local level - where the rubber hits the road. This brings to mind something that Dr. Phyllis Magrab, Director of the Georgetown Child Development Center, suggested in reference to the importance of the local planning process in implementing Part H - " . . . decisions about the control of nuclear arms will be made in the village square."

By calling for an interagency sponsorship of early intervention services and the development of an Individual Family Service Plan (IFSP), rather than an Individual Education Plan (IEP) as was mandated under P.L. 94-142, Congress clearly recognized that the early intervention process is as much a health and social services effort as an educational one. State Title V Programs cannot be bystanders in this movement as they have much leadership to offer as the result of over fifty years of service delivery and resources development related to young children and their families.

Pro-active involvement will become even more critical in view of recent amendments to Title V and Medicaid legislation. Although not finalized at the time of the writing of this Report, these changes include, effective FY 1991:

* A MCH Block Grant application process that is based on a statewide needs assessment.

* Earmarks to provide that 30% of Federal Title V funds will be spent on "Preventive and Primary Care Services for Children" and that 30% will be spent on "Services for Children with Special

Health Care Needs."

* A provision that the State must maintain the level of funding provided solely by the State for MCH/CSHCN Programs at least equal to FY 1989 levels.

* An annual report consistent with detailed reporting requirements.

* A mandate for Medicaid coverage of pregnant women, infants and children up to the age of six with incomes up to 133% of the Federal poverty level.

* A requirement to provide coverage of treatment to correct problems identified in EPSDT screens, even if the services are not covered under the State Medicaid Plan.

These last two initiatives will require State Title V Programs to clearly establish the assurance of quality of care and resources development as the hallmarks of their efforts.

P.L. 99-457 provides us with the opportunity to step back from our usual mode of operation which is so characterized by a categorical and fragmented approach to service delivery, and to scheme with our colleagues in the education and social services community, creative strategies toward a more effective and efficient way of assuring comprehensive services for vulnerable children and their families. Hopefully, it is creating a "healthy tension" in states to move beyond "business as usual."

Although the mandate and regulatory guidance from Part H does not provide us with the all the answers, and certainly not with the funds, we are provided with an unprecedented interagency planning opportunity for making things better through more coordinated efforts which recognize the pivotal role of the family in the decision-making process. As written in the opening lines of one of the favorite stories of the American Family,

"Here is Edward Bear, coming downstairs now, bump, bump, bump, on the back of his head, behind Christopher Robin. It is, as far as he knows, the only way of coming downstairs, but sometimes he feels that there really is another way, if only he could stop bumping for a moment and think of it."

Winnie-the-Pooh

A.A. Milne